

Grant Number DAMD17-94-J-4212

TITLE: Cost Effectiveness of Alternative Treatments for Local Breast Cancer in the Elderly

PRINCIPAL INVESTIGATOR: Jack Hadley, Ph.D.

CONTRACTING ORGANIZATION: Georgetown University
Washington, DC 20057

REPORT DATE: August 1998

TYPE OF REPORT: Final

PREPARED FOR: U.S. Army Medical Research and Materiel Command
Fort Detrick, Maryland 21702-5012

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REPORT DOCUMENTATION PAGE			Form Approved OMB No. 0704-0188	
<small>Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to Washington Headquarters Services, Directorate for Information Operations and Reports, 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302, and to the Office of Management and Budget, Paperwork Reduction Project (0704-0188), Washington, DC 20503.</small>				
1. AGENCY USE ONLY (Leave blank)		2. REPORT DATE August 1998		3. REPORT TYPE AND DATES COVERED Final (1 Aug 94 - 31 Jul 98)
4. TITLE AND SUBTITLE Cost Effectiveness of Alternative Treatments for Local Breast Cancer in the Elderly			5. FUNDING NUMBERS DAMD17-94-J-4212	
6. AUTHOR(S) Jack Hadley, Ph.D.				
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES) Georgetown University Washington, DC 20057			8. PERFORMING ORGANIZATION REPORT NUMBER	
9. SPONSORING / MONITORING AGENCY NAME(S) AND ADDRESS(ES) U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012			10. SPONSORING / MONITORING AGENCY REPORT NUMBER	
11. SUPPLEMENTARY NOTES			<div style="font-size: 2em; font-weight: bold;">19990820 036</div>	
12a. DISTRIBUTION / AVAILABILITY STATEMENT Approved for Public Release; Distribution Unlimited			12b. DISTRIBUTION CODE	
13. ABSTRACT (Maximum 200 words) <p>This project collected data from elderly women (67+) with early stage breast cancer who were treated in 1992-1994. Survey eligibility (confirmed cancer diagnosis and early stage disease) was determined by first conducting a mail/telephone survey of approximately 4,500 surgeons (92.2% response rate for eligible surgeons) regarding over 6,000 women covered by Medicare. 3,406 women were determined eligible, of whom 676 were deceased. Of the remaining eligible cases who were contacted, 1550 (86.9% response rate) completed telephone interviews providing current health status and other socio-demographic information. Medicare claims data for 1991-1996 (1997 data will be added when available) were obtained for the decedents and survey respondents in order to conduct cost-effectiveness analyses (CEA). Initial results indicate that the rate of breast conserving surgery (BCS) was over 60% in each year, 1992-1994. This is much higher than had been suggested by earlier studies. Preliminary cost calculations show that mastectomy is more costly than BCS over the first five months following surgery. Comprehensive CEAs and behavioral analyses of treatment choice will be conducted under a complementary research project, "Care, Costs and Outcomes of Local Breast Cancer in Elderly Women," supported by Grant No. HS-08395 from the Agency for Health Care Policy and Research, USDHHS.</p>				
14. SUBJECT TERMS Breast Cancer			15. NUMBER OF PAGES 76	
			16. PRICE CODE	
17. SECURITY CLASSIFICATION OF REPORT Unclassified	18. SECURITY CLASSIFICATION OF THIS PAGE Unclassified	19. SECURITY CLASSIFICATION OF ABSTRACT Unclassified	20. LIMITATION OF ABSTRACT Unlimited	

FOREWORD

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I. INTRODUCTION: NATURE OF THE PROBLEM AND BACKGROUND

Background

In 1994, 183,000 women developed breast cancer and 47,000 women died of the disease. Forty-four percent of the new cases and 56 percent of the deaths occurred among the 13 percent of the female population which was 65 or older. Thus, more than 80,000 elderly women are diagnosed with breast cancer each year and, based on increased use of screening examinations, upwards of 70 percent of these women should be diagnosed in local stages (Tabar et al., 1985).

As a consequence of this high burden of disease, the elderly incur a disproportionate share of the \$35 billion in annual direct medical costs of cancer in the U.S. In addition, the cost of medical care to the Medicare program for breast cancer survivors is substantial. On average, breast cancer survivors live an additional 11.2 years and incur almost \$54,000 in Medicare costs (Riley et al., 1995). Despite the enormous resources expended on cancer care, little is known about the financial impact of alternative cancer therapies.

Randomized clinical trials of breast cancer therapies conducted in the 1980s have demonstrated that breast conserving surgery (BCS) with radiation therapy (RT) yields equal survival to modified radical mastectomy (MRM) (Bader et al., 1987; Fisher et al., 1985; Fisher et al., 1989). However, few elderly women were included in those trials. Further follow-up of women in the trials indicates that survival rates for local stage disease continue to be equivalent for both treatment modalities, whether or not BCS is accompanied by RT (Early Breast Cancer Cooperative Group, 1995; Fisher et al., 1995). However, local recurrence rates are 30% higher in women who did not receive RT in conjunction with BCS compared to BCS with RT. Although age was not considered a contraindication to either treatment modality (Steinfeld et al., 1989; Balducci et al., 1991), there has been very little direct analysis of the effects of alternative treatment choices on survival or recurrence in the elderly.

In spite of the evidence from clinical trials, the use of BCS by elderly patients varies greatly and appears to be under-used. Estimates from the late 1980s indicate that only 3.5% to 21% of elderly women received BCS; fewer than half of these women received RT (Chu et al., 1987; Yancik et al., 1989; Silliman et al., 1989; Lazovich et al., 1991; Bergman et al., 1991; Farrow et al., 1992; Nattinger et al., 1992; Newcomb and Carbone, 1993). Numerous other studies have documented additional age-related variations in breast cancer treatment (Greenfield et al., 1987; Samet et al., 1986; Silliman et al., 1989; Chu et al., 1987; Lazovich et al., 1991; Bergman, et al., 1991; Farrow et al., 1992), including less aggressive use of intravenous adjuvant chemotherapies (Newcomb and Carbone, 1993; Silliman et al., 1989; Allen et al., 1986; Chu et al., 1987), despite similar rates of toxicities seen in younger patients (Begg and Carbone, 1992), and fewer consultations with medical or radiation oncologists in elderly compared to non-elderly women (Newcomb and Carbone, 1993).

The few cost-effectiveness analyses that have examined treatment of local breast cancer have focused on younger women (Smith and Hillner, 1993), and/or have used data from RCTs (Smith and Hillner, 1993; Hillner and Smith, 1991; Verhoef et al., 1991). The efficacy of treatment and cost observed under RCT conditions are not likely to replicate those expected in actual clinical practice, where the populations are more heterogeneous and treatments less intense (Eisenberg, 1989; Drummond and Davies, 1991; Smith, Hillner, and Desch, 1993). This concern may be particularly germane when addressing the elderly, because of their substantial diversity in health, functional status, and social support. In addition, few breast cancer trials have included elderly women, especially those aged 75 or more. Munoz and colleagues, using 1983-1984 charge data for a case series of 79 women treated in one hospital found BCS and RT to be 37% more expensive than MRM; however, surgeons' fees were 55% higher for the MRM than for the more conservative surgery (1986).

II. BODY

A. Goals and Methods of Approach

1. Goals

The goal of this project is to conduct cost-effectiveness analyses of three treatment modalities for breast cancer (MRM, BCS with RT, and BCS without RT) in elderly women with local disease. Benefits will be based on survival and quality of life measured annually up to five years post-treatment. Costs will be measured from the social perspective and will be based primarily on the direct costs of all medical care. Secondary analyses will consider various substrata of women, based on age (67-75, older than 75), initial health state (derived from comorbidities at time of diagnosis and prior medical care use), place of residence (urban or rural), marital status and living arrangement at time of treatment (alone, with spouse, with others), and hospital type (cancer center, other teaching hospital, nonteaching)

Actual practice may deviate from recommended guidelines for several reasons: elderly women's poorer health generally, preferences and quality of life assessments, fewer social supports, diminished socioeconomic status, transportation difficulties, and poorer access to high-volume breast cancer surgeons and radiation therapy centers. Prior research, which has typically examined only one or two of these elements and has not focused primarily on elderly patients, provides few insights on these questions. By conducting cost-effectiveness analyses that take these factors into account, the proposed project will assess whether elderly women, generally or in particular circumstances, are receiving sub-optimal patterns of care. If they are, our analyses of treatment choice determinants and of the relationship between treatments and outcomes will generate recommendations for policy changes to alter treatment patterns, as well as to provide information for developing clinical guidelines regarding preferred treatment choices under a variety of patient and environmental circumstances.

2. Methods of Approach

At approximately the same time this grant was awarded, Georgetown University received funding from the Agency for Health Care Policy and Research (AHCPR), USDHHS, to conduct a parallel study using data from a different sample of elderly women. After extensive discussions between the research staff and the respective Project Officers from the DoA and AHCPR, it was decided that the interests of both projects would be best served by combining the methodologies and data collection strategies in order to develop a larger sample of cases than could be obtained and analyzed by either research project by itself.

Specifically, it was decided that the resources of the DoA award would be devoted primarily to expanding the samples of women and physicians who would be surveyed as part of a national random sample of elderly women with early stage breast cancer treated between 1992 and 1994. Moreover, in order to incorporate three-to-five years of post-treatment cost information, it was also agreed that the cost-effectiveness analyses and behavioral analyses of these data would be supported primarily by resources from the AHCPR grant during that project's final year, which begins November 1, 1998, after the termination of the period of research supported by this grant from the DoA. Consequently, the results reported in the body of this final report refer primarily to the process of collecting data from the national patient and physician surveys and the addition of data from Medicare claims records for the years 1991 through 1996. (Data for 1997 became available as of July 1998, and have been requested from the Health Care Financing Administration (HCFA) under the AHCPR grant.)

Data will be collected by telephone surveys of a nationally representative sample of 2,000 Medicare beneficiaries who were treated for local breast cancer between 1992 and 1994, and of their surgeons. The patient and physician samples will be drawn from Medicare's 5% Standard Analytic File, which is a nationally representative random sample of all Medicare beneficiaries and

the physicians who treated them. In order to obtain a final sample of 2,000 women, we are contacting approximately 4,500 physicians in order to request information on over 6,000 beneficiaries. The combination of physician nonresponse, patient ineligibility, and patient nonresponse will result in the final sample of 2,000 patients.

The physician survey is being administered by mail with telephone follow-up in two phases: Physicians will be surveyed in order to verify that the patient in fact had breast cancer and to determine the stage of disease. Women with late stage (III or IV) disease are not eligible for the analysis. Women identified as eligible will then be surveyed by telephone to obtain information on current health and basic sociodemographic characteristics. In Phase 2 of the physician survey, the physicians of women who completed interviews will be administered a brief mail survey (with telephone follow-up) to obtain information about their propensities to choose breast conserving surgery and radiation therapy. These propensities are derived from responses to three hypothetical case scenarios.

Medical care use data will come from the Medicare National Claims History file for all respondents, nonrespondents, and decedents. (Cost data for decedents will be used in calculating cost-effectiveness ratios.) The relationship between treatment and outcomes will be estimated using an approach to correct for bias due to the observational nature of the data.

Data for women who are up to two years post-treatment will come from the complementary research project (Care, Costs, and Outcomes of Local Breast Cancer, AHCPR Grant No. HS08395), which is supporting the collection of data for approximately 750 breast cancer patients who are being followed prospectively for up to two years. (The costs of the national physician and patient surveys are being shared by the two projects.)

Cost-effectiveness analysis will be used to combine the costs and outcomes of treatment over the five year evaluation period. Cost-effectiveness ratios will be constructed based upon the

formula $CER_t = \sum \text{Costs}_t / \sum \text{QALYs}_t$ where t =treatment modality (MRM, BCS w/RT, BCS w/o RT). Costs are calculated from Medicare claims and QALYs are calculated from five-year survival curves for each of the three treatment outcomes and patient preference assessments (based upon adjusted patient EuroQol© scores) at approximately years 1, 2, 3, 4, and 5. Preference assessments for time periods between measurements will be interpolated linearly, or extrapolated on a patient age-adjusted basis. We will then divide the treatment survival curve for each of the three therapies into five 12 month segments. We will multiply the average patient months of survival for each portion of the survival curve by the average preference weight for that time period to develop a measure of the total preference-adjusted survival months for each segment of the survival curve. The number of QALYs for each of the three therapies will be taken as the discounted sum of the preference-adjusted survival months of the five curve segments. This method will account for survivor bias in responses to the preference instruments because we will include all patients in the calculations, with patients who die having a preference weight of 0 from the date of death to the end of the observation period.

B. Results

1. National Patient Survey

The National Patient Survey was successfully completed during Year Four. As described in Methods of Approach, identification of a sample of elderly women eligible for the patient survey required conducting a survey of women's surgeons in order to confirm a diagnosis of breast cancer and to determine which women had early stage disease (stages I, IIa, and IIb). In order to reach the target sample of 2000 women with usable data for the cost-effectiveness analyses, we contacted 4,500 surgeons about more than 6,000 elderly Medicare beneficiaries who were identified as either having had a breast surgery procedure and/or a tentative diagnosis of breast

cancer. The surgeons were first contacted by mail, and those who did not return completed eligibility forms or refused were subsequently contacted by telephone. (Appendix 1 is the Patient Eligibility Form completed by patients' surgeons.)

Due to the passage of time between the date of surgery and the time surgeons were contacted, 298 (6.6 percent) surgeons were either in new locations and could not be traced, or had retired or died. Another 345 (7.7 percent) no longer had access to the patient's records and could not provide the needed information; and another 168 (3.7 percent) were either not contacted at all or not followed-up after the initial mailing because the target number of eligible patients had been reached.

Of the remaining 3,689 physicians who were contacted and had access to patients' records, 3,400 (92.2 percent) provided eligibility information for at least one patient. (Sample physicians were queried for up to five potentially eligible Medicare patients; the average number of patients per physician was 1.8). This very high response rate makes it very unlikely that response bias from the physician eligibility phase of the national patient survey will cause bias in subsequent analyses.

The physician survey identified 3,406 women who met the initial criteria for study eligibility: age 67 or older, early stage breast cancer, no prior history of breast cancer, and no bilateral or multicentric cancer. Sample cases were contacted for interviews in random order; 239 (7.0 percent) were not contacted at all because the target number of completed interviews was attained without exhausting the full sample. Of the remaining 3,167 cases, 676 (21.3 percent) were deceased. These cases will be used in the cost-effectiveness analyses, representing 0 quality-of-life at the time of death following surgery for breast cancer. 331 (10.5 percent) were ineligible because of language (not English speaking), residence in a nursing home, or illness, and 377 (11.9 percent) could not be contacted. Of the remaining 1,783 eligible and locatable cases, 1,550 (86.9

percent) completed the telephone interview. (The National Patient Interview Instrument is reported in Appendix 2.)

In all, 2,226 cases are available for the cost-effectiveness analyses (676 decedents and 1,550 women who survived three to five years post-treatment). This total exceeds the projected target of 2,000 eligible women who had been treated between 1992 and 1994. Data for the sample of 1,550 survivors, who completed the telephone interview, will be used to estimate a behavioral model of the determinants of breast cancer treatment choice. The very high patient response rate, in conjunction with the even higher response rate by physicians to the initial eligibility portion of the patient survey, suggests that nonresponse bias is unlikely to be a problem in either the cost-effectiveness or behavioral analyses.

The item response rate for the questions about current health is also very good. Preliminary analysis of responses from women treated in 1992 or 1993 indicate that 98.5 percent reported current general health, 93.6 percent answered the Euroqol question, and 88.3 percent responded the full battery of questions used to construct a utility score. Moreover, responses are broadly distributed across health states. For example, the distribution of responses to the general health question is as follows: excellent (14.2%), very good (27.9%), good (31.6%), fair (19.3%), and poor (5.5%). The Euroqol measure, which is bounded between 0 and 1, has a mean of 0.72 and a standard deviation of 0.22, again suggesting a broad distribution of post-treatment health states.

2. Medicare Claims Data

All Medicare claims for all eligible cases (decedents, respondents, and nonrespondents) were obtained from the HCFA for calendar years 1991 through 1996. (Data for 1997, which is five years post-surgery for women treated in 1992, have been requested under the grant from the AHCPR.) Data for the year prior to surgery (1991 for women treated in 1992) will be used to construct

measures of co-morbidity for the treatment choice analyses. All other claims following the date of surgery will be used to construct information on medical care costs following treatment.

Medicare claims are divided into six different categories of services: inpatient hospital, physician and other Part B services, home health services, hospice, skilled nursing facilities, and outpatient clinics or centers. Costs will be tabulated by month (30-day intervals) from the date of surgery until either death or interview.

Table 1 reports preliminary tabulations for the first five months following surgery for women who had either mastectomy (MRM) or breast conserving surgery (BCS). (Women who had BCS followed by radiation therapy (RT) will be identified by searching the post-surgery claims for the presence of RT claims beginning within six months of the date of surgery. This part of the data base construction is currently underway.)

The figures in Table 1 indicate that women who had a mastectomy had significantly higher costs in the first month following the date of surgery, \$4,097 compared to \$2,256. This was due primarily to much higher costs for inpatient hospital care (\$2,599 compared to \$880) and somewhat greater spending for physicians' services. Mastectomy patients are much more likely than women who had BCS to be hospitalized for at least a one-night stay. The higher spending for physicians' services presumably reflects the higher payment surgeons receive for performing a mastectomy relative to a breast conserving procedure. By five months post-surgery, the monthly costs are very similar, though mastectomy patients have consistently higher inpatient hospital costs in each month. (For the cost-effectiveness analyses, we will also include the month before surgery in order to capture the costs of diagnosis and other pre-operative tests and procedures.) Similar monthly tabulations will be constructed for every month up to either the date of death or the date of interview in 1997.

Table 1

Monthly Medicare Costs by
Type of Surgery and Type of Service

Type of Surgery and Post-Surgery Monthly	Type of Service				
Breast Conserving	Physician	Home Health	Outpatient	Inpatient	Total ^a
1	781	35	560	880	2,256
2	370	46	204	270	890
3	374	37	249	157	817
4	90	40	223	193	746
5	205	30	99	171	505
Mastectomy					
1	1,146	71	321	2,599	4,097
2	398	136	98	586	1,218
3	300	119	97	347	863
4	303	98	97	265	763
5	203	60	68	206	537

Note: a. Excludes hospice and skilled nursing

3. National Physician Survey

The final phase of the national surveys conducted under this grant is a resurvey of surgeons whose patients will be included in the cost-effectiveness analyses in order to administer a brief survey instrument designed to obtain information about surgeons' propensities to perform either MRM or BCS. This measure of surgical propensity is potentially a very important variable for generating a "predicted" treatment choice that is independent of the patient's actual health state.

The national physician resurvey was begun during July 1998 and is still in progress. (The National Physician Survey Instrument is reported in Appendix 3.) It will be completed by October 1998 with resources from the AHCPR grant. Preliminary results indicate that the response rate will be lower than was experienced for the eligibility portion of the survey. There are several reasons for this: no additional honorarium is being offered to the surgeon; the surgeon must respond personally to the hypothetical case scenarios and to the questions about personal and practice characteristics; and the conduct of the survey during the summer months when many surgeons are on vacation makes it harder to reach them for telephone follow-up.

In order to compensate for the anticipated lower response rate, we will develop an imputation algorithm that takes advantage of the information available from Medicare claims for 1994 which were used to draw the initial sample of surgeons. This data base includes all elderly women who had a breast surgery procedure. From this data, we can compute for each surgeon a proxy propensity measure based on the observed proportion of actual cases who received BCS. Preliminary analysis of data from physicians participating in the prospective cohort portion of the project funded by the AHCPR suggests that the observed proportion of BCS cases is a significant predictor of the surgeons' treatment propensity, i.e., the higher the proportion of a surgeon's Medicare breast cancer cases who received BCS, the more likely it is that the surgeon has a propensity for BCS. (These results were reported at the Era of Hope Conference, sponsored by the DoA, October 31-November 4, 1997, Washington DC.) Thus, the claims-based measure of propensity for BCS can be used to impute a propensity for surgeons who fail to respond to the follow-up physician survey.

4. The Trend in the Rate of BCS

Information on the treatment received by eligible respondents in the national survey was combined with information on treatment received by women surveyed as part of the prospective cohort portion of the overall project. Together these two data bases provide estimates of the rate of BCS for the years 1992 through 1996/97. The annual estimates for 1992 through 1994 are based on nationally representative random samples of about 730 women per year. The samples for 1995/96 and 1996/97 are about half the size per year and are not nationally representative. Nevertheless, they provide the most recent survey evidence on the rate of BCS among elderly.

Although still preliminary, the results reported in Table 2 suggest that there has been a major and significant increase in the rate of BCS among elderly Medicare beneficiaries with early stage breast cancer. The most recently available published information, which typically used less precise secondary sources from the late 1980s or very early 1990s suggested that the rate of BCS was generally under 20 percent for elderly Medicare beneficiaries. In contrast, our survey results suggest that the rate is just over 60 percent and has been relatively stable over the period 1992 - 1997.

There are probably two major reasons why our estimates are so much higher than those reported in the literature for just a few years earlier. First, the National Institutes of Health's (NIH) consensus statement regarding the equivalency of BCS and MRM in the treatment of early stage breast cancer was issued in 1989. It may be that surgeons' practice patterns were slow to change immediately following issuance of the guidelines. However, once the guidelines became better known and presumably more acceptable, the change in practice may have responded very quickly.

Table 2

Rate of BCS ^a Women (age 67 or Older) with
Early Stage Breast Cancer, 1992-1997

Year and Sample	Number of Cases	Percentage Receiving BCS
National		
1992	1,137	62.5%
1993	1,168	62.6
1994	1,095	60.3
Convenience ^b		
1996 ^c	434	61.0
1997 ^d	325	64.2

Notes: a. In the national sample BCS identified by a physician/outpatient HCPCS procedure code of 19120, 19160, or 19162, or an ICD-9 inpatient procedure code of 4011, 4023, 8520, 8521, 8522, or 8523; mastectomy is identified by HCPCS codes 19180, 19182, or 19240, or ICD-9 codes 8541, 8543, 8545, 8547, 19200, 19220. For the convenience sample, BCS is identified from the response to the question, "What surgical treatment did you have? Mastectomy, breast conserving surgery, other, or don't know/unsure." Less than 2 percent of respondents responded other or don't know. These cases are excluded.

- b. Eastern Massachusetts, Western New York, New York City, Washington DC metropolitan area, and Texas.
- c. Includes patients treated in November and December, 1995.
- d. Through September 1997.

Second, the estimates reported by earlier studies probably under-estimated the rate of BCS because of limitations in the data on which they were based. Inpatient hospital claims for Medicare beneficiaries do not contain any information on disease stage. Since the rate of BCS is lower for women with advanced-stage disease, failure to exclude these cases would result in downward bias.

In addition, BCS is much more likely to be performed in outpatient settings compared to MRM. Thus, limiting the data to inpatient claims also results in a downward bias in the rate of BCS.

5. Determinants of Treatment Choice

Consistent with the methodology of the AHCPR-funded portion of this project, the analysis of the determinants of treatment choice will first be conducted with the much richer data collected from the prospective cohort of elderly women diagnosed with early stage breast cancer in 1995-1997. Once this analysis is completed, it will provide a benchmark for estimating a more parsimonious version of the treatment choice model using the data collected from the national sample of patients. Estimating the same model with data from the prospective cohort will suggest whether omission of key information not available for the national sample leads to significant bias in the values of the estimated coefficients.

Estimation of the treatment choice model with data from the prospective cohort is currently underway, using the full sample of 753 women. These women were treated between October 1995 and September 1997. As noted above, about 60 percent of the women reported having BCS. Almost 80 percent of those who have BCS also have radiation therapy (RT). As shown in Table 3, the proportion of women receiving BCS+RT falls sharply with age and the likelihood of MRM increases with age: elderly women between the ages of 67 and 74, are 65 percent of the patients with BCS+RT, only 31.4 percent of those BCS alone, and 53 percent of women who had MRM; those 80 or older are only 8.6 percent of cases with BCS+RT, but 41.2 percent of the BCS only cases.

Table 3
Cohort Descriptive Data

	ALL		Crosstabs		
	Number	Percent	BCS w/RT	BCS w/o RT	MRM
Patients, by Treatment	714	1.00%	49.7%	13.2%	37.1%
Age*					
Less than 70	108	15.17%	48.15%	13.89%	37.96%
70-74	263	36.94%	55.13%	7.98%	36.88%
75-79	193	27.11%	57.51%	7.77%	34.72%
80+	148	20.79%	30.41%	29.05%	40.54%
Stage*					
I	370	65.49%	57.84%	11.08%	31.08%
IIA	145	25.66%	41.38%	12.41%	46.21%
IIB	50	8.85%	38.00%	4.00%	58.00%
Systemic Treatment*					
Chemo only	35	12.64%	25.71%	31.43%	42.86%
Tamoxifen only	50	18.05%	62%	8%	30%
Both	19	6.86%	0%	31.58%	68.42%
Neither	173	62.45%	57.23%	12.14%	30.64%
Axillary Node Dissection					
Yes	360	47.12%	68.61%	10%	21.39%
No	404	52.88%	31.93%	16.83%	51.24%
Marital status					
Married	315	44.18%	54.6%	13.33%	32.06%
Divorced/Separated	61	8.56%	54.1%	11.48%	34.43%
Widowed	296	41.51%	44.59%	12.16%	43.24%
Never Married	41	5.75%	41.46%	21.95%	36.59%
Living Arrangement					
Alone	296	41.63%	45.61%	13.51%	40.88%
With Others	415	58.37%	52.53%	13.01%	34.46%
Home Ownership*					
Own home	542	76.12%	52.21%	11.25%	36.53%
Do not own home	170	23.88%	41.76%	19.41%	38.82%

Table 3 (Continued)

	ALL		Crosstabs		
	Number	Percent	BCS w/RT	BCS w/o RT	MRM
Education*					
Less than high school	120	17.02%	34.17%	22.5%	43.33%
High school/some college	421	59.72%	52.49%	11.4%	36.1%
College and above	164	23.26%	54.27%	11.59%	34.15%
Race					
White	631	88.38%	51.03%	12.52%	36.45%
African-American or other	83	11.62%	39.76%	18.07%	42.17%
Monthly Income*					
\$0-999	150	21.01%	39.33%	15.33%	45.33%
\$1,000-1,999	179	25.07%	50.28%	13.97%	35.75%
\$2000-3,999	171	23.95%	49.71%	8.77%	41.52%
\$4,000+	105	14.71%	57.14%	16.19%	26.67%
DK/REF/missing	109	15.27%	55.96%	12.84%	31.19%
Insurance Coverage*					
HMO	179	25.43%	55.31%	13.41%	31.28%
Private	467	66.34%	50.11%	12.42%	37.47%
Other	58	8.24%	31.03%	18.97%	50%
Transportation Problem*					
Yes	113	16.28%	29.2%	13.27%	57.52%
No	581	83.72%	54.04%	13.08%	32.87%
Importance of MD Recommendation*					
Very important	562	80.98%	53.74%	13.17%	33.1%
Secondary importance	82	11.82%	43.9%	10.98%	45.12%
Not important	50	7.2%	18%	12%	70%
Patient's Satisfaction					
Very satisfied	450	79.23%	53.33%	13.56%	33.11%
Not very satisfied	118	20.77%	47.46%	11.02%	41.53%
Cancer Impact					
Major	152	21.56%	52.63%	10.53%	36.84%
Significant	152	21.56%	49.34%	13.16%	37.5%
Some	190	26.95%	54.74%	12.11%	33.16%
Little or none	211	29.93%	44.08%	16.59%	39.34%

Table 3 (Continued)

	ALL		Crosstabs		
	Number	Percent	BCS w/RT	BCS w/o RT	MRM
Treatment Beliefs*					
Mastectomy better	233	36.24%	12.45%	3.43%	84.12%
BCS better	132	20.53%	81.82%	15.91%	2.27%
No difference	278	43.23%	66.55%	16.55%	16.91%
Post treatment general health					
Excellent	119	16.71%	58.82%	10.08%	31.09%
Very good	235	33.01%	50.64%	13.62%	35.74%
Good	233	32.72%	48.5%	12.88%	38.63%
Fair or Poor	125	17.56%	42.4%	16%	41.6%
Given Choice SRG/RT					
Yes	163	49.85%	41.72%	12.88%	45.4%
No	164	50.15%	53.05%	12.8%	34.15%
Information from other sources					
Yes	316	44.38%	53.48%	11.39%	35.13%
No	396	55.62%	46.97%	14.65%	38.38%
Number of Rx					
0—1	569	79.8%	49.91%	13.36%	36.73%
2—3	123	17.25%	47.15%	12.2%	40.65%
4+	21	2.95%	61.9%	9.52%	28.57%
Baseline General Health Status*					
Excellent	189	26.54%	58.73%	10.05%	31.22%
Very Good	220	30.9%	50%	12.73%	37.27%
Good, Fair or Poor	303	42.56%	43.56%	15.51%	40.92%
Bra Size					
A	56	8.03%	44.64%	14.29%	41.07%
B	285	40.89%	48.07%	16.49%	35.44%
C	208	29.84%	49.52%	9.62%	40.87%
D+	148	21.23%	52.7%	12.16%	35.14%
Very satisfied	554	78.03%	50.9%	14.44%	34.66%
Moderately satisfied	72	10.14%	44.44%	9.72%	45.83%
Not satisfied	84	11.83%	47.62%	7.14%	45.24%

Table 3 (Continued)

	ALL		Crosstabs		
	Number	Percent	BCS w/RT	BCS w/o RT	MRM
Sexual Activity					
Sexually active	135	19.23%	54.81%	9.63%	35.56%
Not sexually active	567	80.77%	48.5%	14.29%	37.21%
Diagnosis Method*					
Mammography	398	56.37%	55.28%	14.82%	29.9%
Lump found by Patient	190	26.91%	42.11%	11.58%	46.32%
Lump found by MD	44	6.23%	38.64%	13.64%	47.73%
Other	74	10.48%	48.65%	6.76%	44.59%
	ALL				
	Number	Mean	BCS w/RT	BCS w/o RT	MRM
Pre-Diagnosis Physical function*	694	71.56	76.22	62.01	68.93
Coping styles, fighting spirit	723	60.32	60.94	60.84	59.43
Coping styles, avoidance	717	46.95	45.78	44.89	48.91

+During data cleaning of 743 women, 29 had missing or inconsistent data for key variables. We are in the process of verifying data for these women. Thus row totals may vary for each analysis.

* $p < .05$.

++Chi-square or one way anova's

Table 3 reports several other factors that appear to be significantly related to treatment choice. Education, home ownership, and income all differ significantly among the three treatment choice groups. Overall, health insurance coverage is not significantly related to treatment choice. However, compared to women who have private supplementary insurance, women in HMOs who have BCS are less likely to receive radiation therapy (73 percent compared to 82 percent), and women who have either no supplementary coverage or Medicaid are more likely to receive MRM (59 percent compared to 37 percent). The measures of health status also suggest that women in

poorer health are more likely to receive either MRM or BCS without RT relative to BCS+RT: 41 percent of the women who reported their general health as "good, fair, or poor" prior to their surgery had BCS+RT, compared to 51 percent of the women who said their health was "excellent or very good."

These simple two-way comparisons obviously do not take account of possible correlations among potential independent variables. In particular, many of the measures that appear to be associated with differences in treatment choice are probably also related to age. Of particular interest is the question of whether the association with age leads to a possible age-bias in treatment choices. For example, older women who have the same health and other characteristics as younger women maybe less likely to have the same treatment pattern as younger women. In addition, these comparisons do not control for differences in surgeons' characteristics or market/environment characteristics.

We have made substantial progress in developing and estimating a multivariate model of the basic treatment choice decision. This model develops variables from each of the four major domains identified in the project's basic objectives: clinical, socio-demographic, economic, and beliefs, attitudes and communication. Among the findings from the preliminary analyses, which examine women's choices between breast conserving surgery (BCS) without radiation therapy (RT), BCS with RT, and mastectomy are:

- ▶ age has a U-shaped relationship to the choice of mastectomy relative to BCS with RT, in that the odds of choosing mastectomy go down with age up to age 74, and then increases at age 80 and older; however age has relatively less effect on the choice of BCS with RT compared to BCS without RT the odds of BCS with RT increase with education relative to both of the other treatment options
- ▶ nonwhites and lower income women are more likely to have a mastectomy relative to BCS with RT
- ▶ type of insurance coverage (HMO, Medicare only, Medicare plus supplement, or Medicare plus Medicaid) has relatively little impact, except for women who are also

- covered by Medicaid, which increases the odds of BCS without RT and of mastectomy, relative to BCS with RT
- ▶ the aggregate measures of attitudes, beliefs, and communication appear to have very little impact on treatment choice
- ▶ women with transportation problems are much more likely to have BCS without RT relative to BCS with RT
- ▶ breast size is significantly related to having BCS without RT relative to BCS with RT--women with smaller breasts are more likely to have BCS without RT
- ▶ physicians' propensity to choose mastectomy and/or region affect the treatment received--women who live in Texas, where physicians are much more likely to have a propensity for mastectomy--are in fact more likely to receive mastectomy
- ▶ the impact of disease stage is as expected--women with stage II disease are more likely to receive mastectomy, and slightly less likely to receive BCS without RT relative to BCS with RT, and lastly
- ▶ the impact of comorbidities is somewhat ambiguous and sensitive to how comorbidities are measured.

6. Recommendations

No specific recommendations are made at this time. As described in Methods of Approach, the final analyses with data collected under this grant will be conducted with resources from a companion grant from the AHCPR. Recommendations will be made at the conclusion of that grant period in October 1999.

III. CONCLUSIONS

This project has been very successful in completing a very large national survey of elderly breast cancer patients and determining their post-treatment health status up to five years after surgery. We have also successfully linked all medical care claims data from HCFA for the year prior to surgery up to 1996, which is two to four years post-surgery. (Our request for data for 1997 is currently being processed; data delivery is expected in the fall of 1998.)

Using resources from the companion grant supported by the AHCPR, we do not anticipate any problems in completing the project's analytic goals, which are to calculate cost-effectiveness ratios for three alternative treatment options (BCS+RT, BCS w/o RT, and MRM), and to estimate a behavioral model that identifies factors influencing the treatment choice decision.

Preliminary analysis of the trend in the rate of BCS among the national and prospective-cohort samples suggests that the overall rate of BCS has increased substantially from what it was thought to be in the late 1980s, and that it has remained relatively stable at approximately 55 percent over the period 1992 through 1997. This finding suggests that a major national policy effort to increase the use of BCS in treating early stage breast cancer in elderly women may not be necessary. However, other preliminary analyses currently underway suggest that there are variations in the rate of BCS both by geography and by women's characteristics. Thus, more targeted policy actions may still be appropriate.

In addition, the cost-effectiveness analyses may provide evidence to support efforts to alter the mix of alternatives to BCS+RT. In particular, it is not at all clear whether BCS w/o RT or MRM is the preferred alternative to BCS+RT, when taking women's treatment preferences, their subsequent health states, and post-treatment costs into consideration. Alternatively, the analyses might imply that BCS+RT is underused relative to BCS w/o RT. Refining the focus of the cost-effectiveness analysis in this way is a very important next step in addressing the general policy issue of the most appropriate treatment choice for elderly women with breast cancer. In all likelihood, the answer to this question will depend on patients' specific circumstances. Consequently, the nature of the appropriate policy responses will also depend on understanding the relative importance of alternative factors that may influence treatment choice.

The preliminary analyses of treatment choice indicate that there are variations across geographic areas of the country in the rates of the three treatment options; that the very old are

much more likely to receive BCS w/o RT, but only slightly more likely to receive MRM compared to women between the ages of 67 and 79; that women who have low incomes or do not have private supplementary insurance coverage (including HMO coverage) are less likely to receive BCS+RT; and that African-American women are also significantly less likely to receive BCS+RT. If the cost-effectiveness analyses indicate that a different pattern of treatment choices for these subpopulations would be more appropriate, then the project will be able to make specific policy recommendations that identify the populations which appear to be receiving a sub-optimal pattern of care, and possibly suggest or identify factors that influence the pattern of care received.

Another area of potential policy intervention may derive from the continuing analyses of physicians' treatment propensities. The final analysis with data from the National Physician Survey may confirm the preliminary finding that surgeons do appear to have distinct treatment propensities, and that these propensities are significant determinants of whether a woman receives BCS or MRM. If so, then understanding the factors that affect surgeons' propensities might suggest strategies for influencing surgeons' behavior in order to encourage a pattern of care that is more consistent with the optimal pattern suggested by the cost-effectiveness analyses.

IV. PUBLICATIONS

Christine Berg, M.D. presented a paper titled "Are Surgeons' 'Propensities' Predictors of Breast Cancer Treatment Patterns in Elderly Women?" at the Era of Hope Conference, October 31 - November 4, 1997, which was sponsored by the Department of the Army. The paper presented was coauthored by Steven Edge, M.D., Jack Hadley, Ph.D., Jeanne Mandelblatt, M.D., and Neal Meropol, M.D.

Jack Hadley, Ph.D. presented a paper titled "Effects of Insurance Coverage and Travel Distance on Breast Cancer Patients' Hospital and Local Therapy Choices" at the Era of Hope Conference, October 31 - November 4, 1997, which was supported by the Department of the Army. The paper was coauthored by Jean M. Mitchell, Ph.D.

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V. PROJECT PERSONNEL LISTING

Cost Effectiveness of Alternative Treatments for Local Breast Cancer in the Elderly

Grant No. DAMD17-94-J-4212

<u>Personnel</u>	<u>Role on Project</u>
Jack Hadley, Ph.D.	Principal Investigator
Jeanne Mandelblatt, M.D., M.P.H.	Investigator
Kevin Schulman, M.D., M.B.A.	Investigator
Jon Kerner, Ph.D.	Investigator
Jean Mitchell, Ph.D.	Investigator
Jonathan Javitt, M.D.	Investigator
Karen Gold, Ph.D.	Investigator
Daniel Dorsainvil, Ph.D.	Investigator
Ayah Johnson, Ph.D.	Investigator
Qin Wang, M.S.	Programmer
Andrew Epstein	Programmer
Melissa Harris	Research Assistant
Jayant Rajan	Research Assistant
Sandra Fournier	Financial Administrator
Theresa Jordan	Project Secretary

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Appendix 1
Patient Eligibility Form

ID #:

OPTIONS STUDY

PATIENT ELIGIBILITY FORM

Please indicate if the patient listed below is eligible to be contacted by our interviewers according to the following criteria. Even if the patient is deceased, it is crucial for our calculation of survival rates to determine whether this patient meets the study's eligibility criteria.

Patient Information:

Name:

DOB:

Address:

Procedure Date:

City:

Date Deceased:*

State:

ZIP Code:

Please update below:

Address:

City:

State:

ZIP Code:

Telephone: () -

2. **Yes**, eligible (complete Eligibility Criteria below) ☐

Eligibility Criteria

(please check all that apply):

- ☐ T1, N0, M0
- ☐ T2, N0, M0
- ☐ Invasive or infiltrating cancer

Summary Stage

- ☐ 0 ☐ IIA
- ☐ I ☐ IIB

Staging information obtained by:

- ☐ Pathologic data
- ☐ Clinical data

3. **No**, not eligible (complete Exclusion Criteria below) ☐

Exclusion Criteria

(please check all that apply):

- ☐ No breast cancer
- ☐ Carcinoma in-situ only
- ☐ T3 or T4
- ☐ Summary stage IIIA, IIIB, IV
- ☐ Dermal lymphatic invasion
- ☐ Bilateral breast cancer
- ☐ Multicentric disease
- ☐ Prior history of breast cancer
- ☐ First breast cancer diagnosis earlier than [2 years less than PDATE]

4. Unknown, information not available ... ☐

After completing patient eligibility form(s), please return by mail in the enclosed envelope or Fax:

MAIL OR FAX TO:
 Jeanne Mandelblatt, M.D., M.P.H.
 Division of Cancer and Aging, Georgetown University Medical Center
 2233 Wisconsin Avenue, NW #430, Washington, DC 20007
 (FAX) 202-687-0651

Appendix 2
The National Patient Interview Instrument

Pat ID: _____

Int ID: _____

Site: _____

Date: ____ / ____ / ____

Breast Cancer

*O*UTCOMES AND
*P*REFERENCES FOR
*T*REATMENT
*I*N
*O*LDER WOMEN
*N*ATIONWIDE
*S*URVEY

National Patient Interview Questionnaire- Revised

OPTIONS National Patient Interview Introductory Script

Hello, Ms. [last name only], my name is _____ and I'm working with the OPTIONS Team on a national study of women's health following breast cancer. You should have recently received a letter about this study.

(If acknowledges receipt of letter, say), "I'd like to ask you a few questions about your background, your health, and about your experiences getting breast cancer treatment. It should only take about 30 minutes of your time. I'd like to let you know that your name will not be used or shared in any way. Your participation in this project will not affect your Medicare health insurance benefits or your medical care in any way. You are free to refuse to answer any questions or stop the interview at any time. Do you have any questions before we begin? May I begin?"

(If does not remember letter or denies receipt of letter), "This is part of an ongoing study about how breast cancer and its treatments affect older women's lives. This is the first study to talk to thousands of women 65 and older. What you tell us will be used to educate doctors and other women about the needs and concerns of women 65 and older. Your story may help women like your self who may get breast cancer in the future. Do you have any questions?"

(If questions, go to prompts; if no questions, continue).

"I'd like to let you know that your name will not be used or shared in any way. Your participation in this project will not affect your Medicare health insurance benefits or your medical care in any way. You are free to refuse to answer any questions or stop the interview at any time. Do you have any questions? (If 'yes', see prompts; If 'no', go on with interview) May I begin?" (If 'yes', begin interview; If 'no', go into conversion script.)

PROMPTS IF QUESTIONS:

FUNDING:

This study is being led by Georgetown University Medical Center in Washington, DC and is funded by the federal government.

CONFIDENTIALITY

All of your responses are confidential. Your name or other identifying information will not be linked with your answers. Your answers are grouped with those of other women and used for the purposes of the study only.

PURPOSE OF THE STUDY

This is part of an ongoing study about treatments for breast cancer and their effects on women's lives. The information will be used to educate other women and their doctors about how treatment affects women's lives.

HOW LONG WILL THIS TAKE

It depends on your answers. On average the interview takes about 25 to 30 minutes.

DO I HAVE TO ANSWER ALL OF THE QUESTIONS?

You are free to refuse to answer any questions or to stop the interview at any time. There are no right or wrong answers to the questions. We are interested in your opinions and experiences

WHO CAN I CALL TO MAKE SURE THIS IS A LEGITIMATE STUDY?

Audrey McDonald at 1-800-685-7623

ALL CASES:

May I go on with the interview?

IF YES, Proceed to Screener Question

IF NO:

"I understand you do not wish to participate in this study. May I, however, ask you to answer a few quick questions for me? Your cooperation would be deeply appreciated."

IF SHE REFUSES, GO TO END STATEMENT.

IF SHE ALLOWS US TO CONTINUE, GO ON:

1. Could you please tell me the reason you don't want to be in this study?

Too busy.01
Too Ill.02
Uninterested.03
REFUSED TO GIVE REASON.99
Other (specify) _____ 88

GO TO END STATEMENT

IF SHE AGREES TO PARTICIPATE:

SCREENER QUESTION:

1. Were you living in a nursing home at the time of your breast cancer diagnosis?

Yes.01 (GO TO END STATEMENT)
No.00 (CONTINUE WITH INTERVIEW)
UNKNOWN.99

Include? _____ (CONTINUE WITH INTERVIEW)

Exclude? _____ (INDICATE REASONS BELOW)

END STATEMENT: Thank you for your time. Those are all of my questions.

Reasons:

- 01.No cancer diagnosis
- 02.Non-English speaking
- 03.Cognitive impairment
- 03.Physical impairment/Too ill
- 04.Non-community dwelling or institutionalized
- 05.Bilateral primary cancer
- 06.Recurrent breast cancer
- 88.Other (specify) _____
- 99.Unsure

Time Interview Started: ____:____ AM/PM
Interviewer Initials: ____
Interviewer Race: ____

Section I — SOCIO-DEMOGRAPHICS

INTRODUCTION: The first section of the interview is about your general background. It will help us better understand your situation and how breast cancer has affected your life. After these questions, we will ask about your health and how you are doing now. Finally we will ask you some questions about what it has been like for you when you have visited doctors. Your name and other identifying information is kept separate from your answers and your answers will never be shared individually with anyone, including your doctor.

1. When you had your surgery in [SDATE] did you live... (READ CHOICES)

By yourself?	01 (SKIP TO 2)
With others?	02
REFUSAL	99
DON'T KNOW/UNSURE	88

1a. Who was living with you then? (PROMPT BY READING IF NECESSARY--
CHECK ALL THAT APPLY)

Spouse or partner, with children	01
Spouse or partner, without children	02
Children	03
Roommates	04
Paid home health aide/nurse	05
Other family members	06
Grandchild(ren)	07
OTHER (SPECIFY) _____	77
REFUSAL	99
DON'T KNOW/UNSURE	88

2. When you had your surgery in [SDATE] what was the zip code where you lived?

3. When you had your surgery in [SDATE], did you... (READ CHOICES)

Own a house 01
Own a condo or co-op 02
Rent a house 03
Rent an apartment 04
Live with a relative who owns 05
Live with a relative who rents 06
HOMELESS 07
OTHER (SPECIFY) _____ 77
REFUSAL 99
DON'T KNOW/UNSURE 88

3a. Do you still live in the same place as you did at the time of your surgery?

Yes 01
No 02

4. At the time of your surgery in [SDATE], were you married, divorced, separated, widowed, or had you never been married?

Married 01
Divorced 02
Separated 03
Widowed 04
Single (never married) 05
OTHER (SPECIFY) _____ 77
DON'T KNOW/UNSURE 88

Now I have a question about people you can talk to.

4a. Right now, about how many close friends and close relatives do you have (people you feel at ease with and can talk to about what's on your mind)?

____ Number

4a1. Of these, with how many have you talked about your breast cancer?

____ Number

5. What is the highest grade or level of schooling you have completed?

- No formal schooling 00
- Elementary:
- 1st grade 01
- 2nd grade 02
- 3rd grade 03
- 4th grade 04
- 5th grade 05
- 6th grade 06
- 7th grade 07
- 8th grade 08
- High School:
- 9th grade 09
- 10th grade 10
- 11th grade 11
- 12th grade or GED 12
- College and Graduate/professional School:
- 1 year 13
- 2 years 14
- 3 years 15
- 4 years 16
- 5 years 17
- 6 or more years 18
- Post-High School Training Other Than College (e.g.
Vocational or Technical Training) 66
- OTHER (SPECIFY) _____ 77
- REFUSAL 99
- DON'T KNOW/UNSURE 88

6.^{NHIS} What is your race or ethnic background, for instance Black, White, Hispanic, Asian?
(RECORD VERBATIM THEN RECODE)

Specify _____

- Black (non-Hispanic) 01
- White (non-Hispanic) 02
- Hispanic (Puerto Rican, Cuban, Mexican, Chicano,
Other Latin American, or Other Spanish) 03
- Aleut, Eskimo, or American Indian 04
- Asian / Pacific Islander 05
- OTHER (SPECIFY) _____ 77
- REFUSAL 99
- DON'T KNOW/UNSURE 88

- 6a. In what country were you born?
Country of birth ____ (Use country coding from list below)

COUNTRY	CODE	COUNTRY	CODE
USA	01	Central American	06
Puerto Rico	02	Haiti	07
Cuba	03	Jamaica	06
Dominican Republic	04	Other Caribbean Island	09
South American	05	African Country	10
Spain	11	Other country (Specify)	77
Unknown	88	Refused	99

- 6b. (If not born in the United States), how old were you when you moved to the United States?

_____ Years

7. Now I am going to read some monthly income categories for you to select from. We ask this because studies have shown that income can affect how people use medical services. About how much money do you have coming in each month from jobs, retirement plans, social security, and/or social services for you (and your spouse)? I'll read the categories..

Less than \$500 01
 \$500 to \$999 02
 \$1,000 to \$1,999 03
 \$2,000 to \$2,999 04
 \$3,000 to \$3,999 05
 \$4,000 or more 06
 REFUSED 99
 DON'T KNOW/UNSURE 88

These next questions are about your health insurance coverage. Health insurance can also affect how people use medical services.

8. When you had surgery in [SDATE], in addition to Medicare that pays for hospital bills (Part A) did you have...

	Yes	No	Don't know
8a. Medicare that covers doctors (that you paid for monthly)? (Part B)	01	00	99
8b. Medicaid?	01	00	99
8c. Any private insurance or a plan that picks up what Medicare doesn't pay? PROBE: This is called a Medigap or supplemental policy	01	00	99
8d. Please give me the full name of this insurance Specify _____	01	00	99

9. Are you now enrolled in an HMO or other form of managed care?
PROBE: An HMO or Health Maintenance Organization is a health plan that requires you to use its doctors. If you use a doctor outside the health plan, then you have to pay most of the cost yourself.

Yes 01
No 00 (SKIP TO SECTION II)
REFUSED 88 (SKIP TO SECTION II)
DON'T KNOW/UNSURE 99

Section II — TREATMENT

INTRODUCTION: Now I'd like to ask you some questions about your surgery in [SDATE] and the treatment you may have had for your breast cancer since [SDATE].

1. In [SDATE], what kind of surgery did you have (READ CHOICES)

Removal of the entire breast (mastectomy) 01
Removal of the lump only
(lumpectomy, breast conserving surgery) 02
REFUSED 99
DON'TKNOW 88

1a. Which side was your surgery on?

Right 01
Left 02
REFUSED 99
DON'T KNOW 88

1b. Are you mainly right handed or left handed?

Right 01
Left 02
REFUSED 99
DON'T KNOW 88

Now I'd like to ask you some questions about treatments you may have received for your breast cancer since the time of your surgery in [SDATE].

1c. Did you receive radiation treatment in the first nine months after your surgery?

PROBE: That would be between [SDATE] and [SDATE + 9 months]

Yes 01
No 00 (SKIP TO 2)
REFUSED 99 (SKIP TO 2)
DON'T KNOW/UNSURE 88 (SKIP TO 2)

1c1. How many weeks of treatment did you have?

_____ Weeks

1c2. Was this the full treatment the doctor recommended?

Yes 01
No 00
REFUSED 99
DON'T KNOW/UNSURE 88

2. Do you feel you were given a choice about the types of surgeries or radiation treatments you received?

Yes 01
No 00
DON'T KNOW 88
REFUSED 99

- 2a. Did you receive chemotherapy at any time in the first nine months after your surgery?
PROBE: That would be between [SDATE] and [SDATE + 9 months].
PROBE: Chemotherapy that is received intravenously.

Yes 01
No 00 (SKIP TO 3)
REFUSED..... 99 (SKIP TO 3)
DON'T KNOW/U NSURE 88 (SKIP TO 3)

- 2a1. How many weeks of treatment did you receive?

_____ Weeks

- 2a2. Was this the full treatment the doctor recommended?

Yes 01
No 00
REFUSED..... 99
DON'T KNOW/UNSURE 88

3. Considering your feelings about (your overall satisfaction with) your surgery and other breast cancer treatment, would you say you...(READ CHOICES)

Are very satisfied? 01
Are somewhat satisfied? 02
Have mixed feelings? 03
Are somewhat dissatisfied? 04
Are very dissatisfied? 05
REFUSED..... 99
DON'T KNOW..... 88

4. Considering your overall health, how would you rate the impact of breast cancer on your life? Would you say it has had...(READ CHOICES)

A major impact? 01
A significant impact? 02
Some impact? 03
Almost no impact? 04
No impact? 05
REFUSED 99
DON'T KNOW/UNSURE 88

Now I'd like to ask you some questions about other things you may have experienced since the time of your surgery in [SDATE].

5. Have you participated in any other breast cancer research studies either for treatment or by being interviewed?

Yes..... 01
No.....00

6. Since your diagnosis, have you taken tamoxifen at any time, or do you have plans to take tamoxifen in the future?

Yes, currently taking 01
Yes, have taken but not currently taking 02
Yes, plan to take in the future 03
No 00 (SKIP TO 7)
REFUSED 88 (SKIP TO 7)
DON'T KNOW/UNSURE 99 (SKIP TO 7)

- 6a. What dates (did you take tamoxifen/do you plan to take tamoxifen)?

What is (was) the start date: ____/____/____
(MM/YY)

And when (did/will) it end or are you still receiving treatment?

____/____/____
(MM/YY) (IF ONGOING CODE 00/00)

- 6b. Since your surgery in (SDATE), have you had a mammogram?

Yes.....01
No00
REFUSED..... 99
DON'T KNOW/UNSURE..... 88

6b1. What was the date of your most recent mammogram?

____/____/____ (MM/YY)

7. Has your breast cancer come back since surgery?

Yes 01
No 00 (SKIP to 8)
REFUSED 99 (SKIP to 8)
DON'T KNOW/UNSURE 88 (SKIP to 8)

7a. In what part(s) of your body has your breast cancer come back?

Same breast 01
Opposite breast 02
Both breasts 03
Chest or lung 04 (SKIP TO 8)
Head/brain 05 (SKIP TO 8)
Bone 06 (SKIP TO 8)
Liver 07
Chest wall/skin area 08
Other (specify) _____ 77 (SKIP TO 8)

7a1. Did your doctor tell you whether the cancer was a new cancer or a return of the original cancer?

New cancer. 01
Return of the original cancer. 02
REFUSED. 99
DON'T KNOW/UNSURE. 88

8.^{JK} After your surgery in [SDATE], did you have any problems getting to your doctor's office for check-ups or going for tests?

Yes 01
No 02
REFUSED 99
DON'T KNOW/UNSURE 88

9. Was the doctor who performed your breast surgery in [SDATE] male or female?

Male 01
Female 02

9a. What is the race or ethnicity of this doctor? PROBE: Please tell me what you think his or her race or origin is/was.

Black 01
White 02
Latino/Hispanic ... 03
Asian 04
Caribbean 05
Indian 06
Other (specify) _____ 77
REFUSED 99
NOT SURE/DON'T KNOW 88

ABM10. The following questions ask about the experiences you usually had when you saw the doctor that performed your breast cancer surgery.

	always	often	sometimes	never
10a. How often did you ask questions of the doctor? (READ CHOICES)	01	02	03	04
10b. How often did what the doctor told you make sense? (READ CHOICES)	01	02	03	04
10c. How often did you feel intimidated (frightened) by the doctor? (READ CHOICES)	01	02	03	04

11. Would you describe your past experiences with the doctors that cared for your breast cancer as....

Mostly positive 01
Somewhat positive 02
Somewhat negative 03
Mostly negative 04
REFUSED 99

Section III — HEALTH STATUS

Now I'd like to ask about your general health *at present*.

1.^{MOS} In general, would you say your health *now* is...

Excellent? 01
Very Good? 02
Good? 03
Fair? 04
Poor? 05

2.^{MOS} The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?

Activity	Yes, limited a lot	Yes, limited a little	No, not limited at all
2a. <i>Vigorous activities</i> , such as running, lifting heavy objects, participating in strenuous sports.	01	02	03
2b. <i>Moderate activities</i> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	01	02	03
2c. Lifting or carrying groceries.	01	02	03
2d. Climbing <i>several</i> flights of stairs.	01	02	03
2e. Climbing <i>one</i> flight of stairs.	01	02	03
2f. Bending, kneeling, or stooping.	01	02	03
2g. Walking <i>more than a mile</i> .	01	02	03
2h. Walking <i>several blocks</i> .	01	02	03
2i. Walking <i>one block</i> .	01	02	03
2j. Bathing or dressing yourself.	01	02	03

- 3.^{MOS} During the *past four weeks* have you had any of the following problems with your work or other regular daily activities *as a result of your physical health*?

Activities	Yes	No	Don't know
3a. Cut down on the <i>amount of time</i> you spent on work or other activities?	01	00	99
3b. <i>Accomplished less</i> than you would like?	01	00	99
3c. Were limited in the <i>kind</i> of work or other activities?	01	00	99
3d. Had <i>difficulty</i> performing work or other activities? (For example, it took extra effort)	01	00	99

- 4.^{MOS} During the *past four weeks* have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

Activities	Yes	No	Don't know
4a. Cut down on the <i>amount of time</i> you spent on work or other activities?	01	00	99
4b. <i>Accomplished less</i> than you would like?	01	00	99
4c. Didn't do work or other activities as <i>carefully</i> as usual?	01	00	99

- 5.^{MOS} During the *past four weeks*, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

Not at all 01
Slightly 02
Moderately 03
Quite a bit 04
Extremely 05
Not applicable 06

- 6.^{MOS} How much bodily **pain** have you had during the *past four weeks*?

None 01
Very mild 02
Mild 03
Moderate 04
Severe 05
Very severe 06

- 7.^{MOS} During the *past four weeks*, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

Not at all 01
Slightly 02
Moderately 03
Quite a bit 04
Extremely 05
Not applicable 06

These questions are about how you feel and how things have been with you during the *past four weeks*. For each question, please give the one answer that comes closest to the way you feel. The answer choices are all of the time, most of the time, a good bit of the time, some of the time, a little of the time, and none of the time.

8.^{MOS} How much of the time during the past four weeks...

Questions	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
8a. Did you feel full of pep?	01	02	03	04	05	06
8b. Have you been a very nervous person?	01	02	03	04	05	06
8c. Have you felt so down in the dumps nothing could cheer you up?	01	02	03	04	05	06
8d. Have you felt calm and peaceful?	01	02	03	04	05	06
8e. Did you have a lot of energy?	01	02	03	04	05	06
8f. Have you felt downhearted and blue?	01	02	03	04	05	06
8g. Did you feel worn out?	01	02	03	04	05	06
8h. Have you been a happy person?	01	02	03	04	05	06
8i. Did you feel tired?	01	02	03	04	05	06
8j. Has your health limited your social activities (like visiting with friends or close relatives?)	01	02	03	04	05	06

9.^{JRW} Since the time of your surgery for breast cancer in (SDATE) have you experienced any loss of arm movement on the side of surgery?

Yes 01
No 02
REFUSED 99
DONT KNOW/UNSURE 88

9a. IF 'YES', ASK: Does that bother you not at all, slightly, moderately, quite a bit, or extremely?

- Not at all 01
- Slightly 02
- Moderately 03
- Quite a bit 04
- Extremely 05

SECTION IV- EUROQUOL

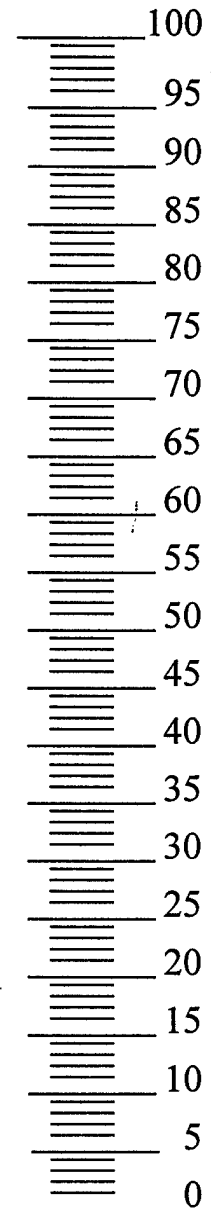
Preferences

1. To help us understand how good or bad your health is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked by 100, and death by 0. Now I would like you to tell me where on this scale I should put how good or how bad your own overall health is *today*, in your opinion, considering all your medical conditions. You can choose any number from '100', the best state of health you can imagine to '0' indicating death.

BEST IMAGINABLE HEALTH STATE

Your own
health
state *today*

Number _____



DEATH

Section V — UTILITIES¹

INTRODUCTION: This set of questions also asks about your day to day health during the *past four weeks*. Some of these questions may not apply to you, but it is important that we ask the same questions of everyone. For some of the questions, I want you to tell me which statement *most closely describes* how you felt.

1.^{HUI} Are you able to see well enough *without* glasses or contact lenses to read the newspaper?

Yes 1 (SKIP TO 2)

No 0

1a.^{HUI} Which of the following best describes your usual ability to see well enough to read the newspaper? Are you...(READ CHOICES)

Able to see well enough, *but with* glasses
or contact lenses? 1

Unable to see well enough, *even with* glasses
or contact lenses? 2

Unable to see at all? 3

2.^{HUI} Are you able to see well enough *without* glasses or contact lenses to recognize a friend on the other side of the street?

Yes 1 (SKIP TO 3)

No 0

2a.^{HUI} Which *one* of the following best describes your usual ability during the past four weeks to see well enough to recognize a friend on the other side of the street?
Would you say you...(READ CHOICES)

Can see well enough with glasses or
contact lenses? 1

Cannot see well enough even with glasses
or contact lenses? 2

Cannot see at all? 3

¹15Q HUI, McMaster University, Torrance et al. with permission

3.^{HUI} Are you able to hear what is said in a group conversation with at least three other people *without* a hearing aid?

Yes 1 (SKIP TO 4)
No 0

3a.^{HUI} Which *one* of the following best describes your usual ability during the past four weeks to hear what is said in a group conversation with at least three other people? Would you say you...(READ CHOICES)

Can hear what is said with a hearing aid? 1
Cannot hear what is said even with a hearing aid? 2
Cannot hear what is said, but don't wear a hearing aid? ... 3
Cannot hear at all? 4

4.^{HUI} Are you able to hear what is said in a conversation with one other person in a quiet room *without* a hearing aid?

Yes 1 (SKIP TO 5)
No 0

4a.^{HUI} Which *one* of the following best describes your usual ability during the past four weeks to hear what is said in a conversation with one other person in a quiet room? Would you say you...(READ CHOICES)

Can hear what is said with a hearing aid? 1
Cannot hear what is said even with a hearing aid? 2
Cannot hear what is said, but don't wear a hearing aid? ... 3
Cannot hear at all? 4

5.^{HUI} Are you able to be understood when speaking the same language with strangers?

Yes 1 (SKIP TO 6)
No 0

5a.^{HUI} Which *one* of the following best describes your usual ability during the past four weeks to be understood when speaking the same language with strangers? Would you say you are...(READ CHOICES)

Able to be understood partially? 1
Unable to be understood? 2
Unable to speak at all? 3

6.^{HUI} Are you able to be understood when speaking the same language with people who know you well?

Yes 1 (SKIP TO 7)
No 0

6a.^{HUI} Which *one* of the following best describes your usual ability during the past four weeks to be understood when speaking with people who know you well? Would you say you are...(READ CHOICES)

Able to be understood completely? 1
Able to be understood partially? 2
Unable to be understood? 3
Unable to speak at all? 4

7.^{HUI} Which *one* of the following best describes how you usually feel? Would you say you are...(READ CHOICES)

Happy and interested in life? 1
Somewhat happy? 2
Somewhat unhappy? 3
Very unhappy? 4
So unhappy that life is not worthwhile? 5

8.^{HUI} Are you free of pain and discomfort?

Yes 1 (SKIP TO 9)
No 0

8a.^{HUI} Which *one* of the following best describes your usual level of pain and discomfort during the past four weeks? Would you say you...(READ CHOICES)

Have mild to moderate pain or discomfort
that prevents no activities? 1
Have moderate pain or discomfort that prevents
a few activities? 2
Have moderate to severe pain or discomfort
that prevents some activities? 3
Have severe pain or discomfort that prevents
most activities? 4

9.^{HUI} Are you able to walk around the neighborhood without difficulty and without walking equipment (such as a cane or walker)?

Yes 1 (SKIP TO 10)
No 0

9a.^{HUI} Which of the following best describes your usual ability during the past four weeks to walk? Would you say you are...(READ CHOICES)

- Able to walk around the neighborhood with difficulty, but without walking equipment or a helper? 1
- Able to walk around the neighborhood with walking equipment, but without a helper? 2
- Able to walk only short distances with walking equipment, and require a wheelchair to get around the neighborhood? 3
- Unable to walk alone, even with walking equipment; able to walk short distances with a helper, and require a wheelchair to get around the neighborhood? 4
- Unable to walk at all? 5

10.^{HUI} Do you have full use of two hands and ten fingers?

- Yes 1 (SKIP TO 11)
- No 0

10a.^{HUI} Which *one* of the following best describes your usual ability during the past four weeks to use your hands and fingers? (NOTE: SPECIAL TOOLS REFER TO HOOKS FOR BUTTONING CLOTHES, TOOLS FOR OPENING JARS OR LIFTING SMALL ITEMS) Would you say you have...(READ CHOICES)

- Limited use of hands or fingers, but do not require special tools or the help of another person? 1
- Limited use of hands or fingers, independent with use of special tools (do not require the help of another person)? 2
- Limited use of hands or fingers, require the help of another person for some tasks (not independent even with the use of special tools)? 3
- Limited use of hands or fingers, require the help of another person for most tasks (not independent even with the use of special tools)? 4
- Limited use of hands or fingers, require the help of another person for all tasks (not independent even with the use of special tools)? 5

11.^{HUI} Are you able to remember most things?

Yes 1 (SKIP TO 12)
No 0

11a.^{HUI} Which *one* of the following best describes your usual ability during the past four weeks to remember things? Would you say you are...(READ CHOICES)

Somewhat forgetful? 1
Very forgetful? 2
Unable to remember anything at all? 3

12.^{HUI} Are you able to think clearly and solve day to day problems?

Yes 1 (SKIP TO 13)
No 0

12a.^{HUI} Which *one* of the following best describes your usual ability during the past four weeks to think and solve day to day problems? Would you say you...(READ CHOICES)

Have a little difficulty when trying to think
and solve day to day problems? 1
Have some difficulty when trying to think
and solve day to day problems? 2
Have a great deal of difficulty when trying
to think and solve day to day problems? 3
Are unable to think or solve day to day problems? 4

13.^{HUI} Do you eat, bathe, dress and use the toilet normally?

Yes 1 (SKIP TO 14)
No 0

13a.^{HUI} Which *one* of the following best describes your ability during the past four weeks to perform these basic activities? Would you say you...(READ CHOICES)

Eat, bathe, dress and use the toilet independently
with difficulty? 1
Require mechanical equipment to eat, bathe,
dress or use the toilet independently? 2
Require the help of another person to eat, bathe,
dress or use the toilet? 3

14.^{HUI} Are you generally happy and free from worry?

Yes 1 (SKIP TO 15)
No 0

14a.^{HUI} Which *one* of the following best describes how you usually feel during the past four weeks? Would you say you are...(READ CHOICES)

Occasionally fretful, angry, irritable, anxious
or depressed? 1
Often fretful, angry, irritable, anxious or depressed? 2
Almost always fretful, angry, irritable, anxious
or depressed? 3
Extremely fretful, angry, irritable, anxious or
depressed, usually requiring hospitalization
or psychiatric institutional care? 4

15.^{HUI} Are you free of pain and discomfort?

Yes 1 (SKIP TO 16)
No 0

15a.^{HUI} Which *one* of the following best describes your usual level of pain during the past four weeks? Would you say you...(READ CHOICES)

Have occasional pain, with discomfort relieved by
non-prescription drugs or self-control activity
without disruption of normal activities? 1
Have frequent pain, with discomfort relieved by oral
medicines with occasional disruption of
normal activities? 2
Have frequent pain, with frequent disruption of normal
activities, and discomfort that requires
prescription narcotics for relief? 3
Have severe pain, that is not relieved by drugs and
constantly disrupts normal activities? 4

Section VI -- PERCEPTION OF HEALTH CARE SYSTEM

In this last section I'd like to ask your opinion about medical care in general and about how things went when you have visited the doctor. I'd like to remind you that all of your answers are confidential and there are no right or wrong answers to any question. We are interested in your opinion.

PSQ181. First, I'm going to read you some things people say about medical care. We are interested in how good or bad you feel about the overall medical care you have received. Please indicate how strongly you agree or disagree with each of the following statements. Your choices are; strongly agree, agree, uncertain, disagree, or strongly disagree.

	strongly agree	agree	uncertain	disagree	strongly disagree	REFU
1a. Doctors are good about explaining the reasons for medical tests	01	02	03	04	05	99
1b. I think my doctor's office has everything needed to provide complete medical care	01	02	03	04	05	99
1c. The medical care I have been receiving is just about perfect	01	02	03	04	05	99
1d. Sometimes doctors make me wonder if their diagnosis is correct	01	02	03	04	05	99
1e. I feel confident that I can get the medical care I need without being set back financially	01	02	03	04	05	99
1f. When I go for medical care, they are careful to check everything when treating and examining me	01	02	03	04	05	99
1g. I have to pay more for my medical care than I can afford	01	02	03	04	05	99
1h. I have easy access to the medical specialist I need	01	02	03	04	05	99

1l. Where I get medical care, people have to wait too long for emergency treatment	01	02	03	04	05	99
1j. Doctors act too business like and impersonal toward me	01	02	03	04	05	99
1k. My doctors treat me in a very friendly and courteous manner	01	02	03	04	05	99
1l. Those who provide my medical care sometimes hurry too much when they treat me.	01	02	03	04	05	99
1m. Doctors sometimes ignore what I tell them	01	02	03	04	05	99
1n. I have some doubts about the ability of doctors who treat me.	01	02	03	04	05	99
1o. Doctors usually spend plenty of time with me	01	02	03	04	05	99
1p I find it hard to get an appointment for medical care right away	01	02	03	04	05	99
1q. I am dissatisfied with some things about the medical care I receive	01	02	03	04	05	99
1r. I am able to get medical care whenever I need it	01	02	03	04	05	99

AMG2. The following questions ask about the experiences you usually have when you see doctor(s).

	always	often	sometimes	never	REFUSED
2a. How often do you ask questions of doctors?	01	02	03	04	99
2b. How often does what doctors tell you make sense?	01	02	03	04	99
2c. How often do you feel intimidated (frightened) by doctors?	01	02	03	04	99

3. Would you describe your past experiences with health care providers in general as....

Mostly positive 01
Somewhat positive 02
Somewhat negative 03
Mostly negative 04
REFUSED 99

AK 4. Now I'd like to ask you some questions about medical care in our country in general.

	strongly agree	somewhat agree	somewhat disagree	strongly disagree	REFUSED
4a. In general, I feel that women do not receive as good quality medical care as men in this country	01	02	03	04	99
4b. In general, I feel that older people do not receive as good quality medical care as younger people in this country	01	02	03	04	99
4c. In general, I feel that poorer people do not receive as good quality medical care as people who are well off in this country	01	02	03	04	99
4d. In general, I feel that Black people do not receive as good quality medical care as white people in this country	01	02	03	04	99

NK 5. How often has each of the following happened to you when getting health care. How often were you discriminated against in getting medical care because...

Would you say..

	frequently	sometimes	once	never	REFUSED
5a. Of your age	01	02	03	04	99
5b. You are a woman	01	02	03	04	99
5c. Of your race or ethnicity	01	02	03	04	99
5d. Of your income	01	02	03	04	99

MAMMO USE 6. Now I am going to read you some statements about perceptions of discrimination in the health care system. For each statement I read, I'd like to you tell me if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree with what I say.

	strongly agree	somewhat agree	somewhat disagree	strongly disagree	REFUSED
6a. Older women (over 65) experience negative attitudes when they go to a young doctor's office	01	02	03	04	88
6b. In most hospitals, older women (over the age of 65) and younger women (less than 65) get the same kind of care	01	02	03	04	88
6c. Older women (over the age of 65) can receive the care they want as equally as younger women (less than the age of 65)	01	02	03	04	88
6d. Older women (over the age of 65) have fewer options for health care than younger women (less than 65)	01	02	03	04	88
6e. Doctors treat older women (over 65) and younger women (less than 65) the same	01	02	03	04	88

Patient ID ____/____/____/____
National Survey

	strongly agree	somewhat agree	somewhat disagree	strongly disagree	REFUSED
6f. Black women experience negative attitudes when they go to a White doctor's office	01	02	03	04	88
6g. In most hospitals, Black women and White women get the same kind of care	01	02	03	04	88
6h. Black women can receive the care they want as equally as White women	01	02	03	04	88
6i. Black women have fewer options for health care than White women	01	02	03	04	88
6j. Doctors treat Black and White women the same	01	02	03	04	88

7. Looking back on your experiences and treatment decisions, what advice would you offer other women your age when they are deciding on what breast cancer treatment to get?

Go to a good MD/Hospital	01
Go to the best MD.	01
Go to a MD you trust/ have faith in	01
Go to the best hospital	01
Go to a cancer clinic	01
Go to a teaching facility	01
Go to an oncologist	01
Ask family/ MD/ friends to recommend a surgeon ..	01
 Communicate with doctors	02
Listen to the doctor.	02
Do what the doctor recommends	02
Talk to doctors.	02
Trust your doctor.	02
 Make your own choices	03
Make your own decision/ choice	03
Do what's best for you/ Do what makes you happy .	03
Decide for self	03
Don't talk with anyone	03
 Gather information	04
Check out all your options	04
Get a second opinion	04
Ask questions/ Educate yourself	04
Do not listen to old wives tales	04
Talk with others	04
Read	04
 Maintain a positive attitude	05
Do not be afraid	05
Lead a normal life	05
Rest and be careful	05
Don't dwell on it	05
Think positive	05
Don't make a big deal of	05
 Spirituality	06
Pray/ trust in the Lord.	06

Act promptly	07
Do not delay	07
Get rid of cancer ASAP	07
Get medical attention	07

Specific Screening/Treatment Recommendations. .08-00

Get a mastectomy.	08
Get radiation therapy	09
Get breast conserving surgery/lumpectomy/don't get mastectomy unless you need it/don't have radical unless you need it ...	10
Get Tamoxifen.	11
Get chemotherapy.	12
Do what I did [interviewer: find out what she did and record that].	13
Have (regular) mammograms.	14
No advice/can't say.	15
No surgery.	16

Communicate with family	17
Talk to your family/spouse.	17

Get needed medical attention	18
Do whatever's necessary	18
Get necessary treatment	18

Miscellaneous other	00
----------------------------------	----

8. What would you tell doctors caring for women with breast cancer like yourself?

Respect/Caring.	01
Be understanding/compassionate/ gentle.	01
Be honest.	01
Treat patients good.	01
Take the time.	01
Take the patients seriously.	01
Be open to questions.	01
Treat patients fairly/ Treat patients like adults.	01
Be available/ accessible to patients.	01
Listen.	01
Be sensitive.	01
Look in patients' eyes.	01
Give women time.	01
Offer spiritual guidance.	01
Be professional.	01
 Talk directly to patients.	 02
Talk directly to patients not others (e.g.. relatives). . .	02
 Choice.	 03
Give patient a choice/ option.	03
Tell patients to make the best choice.	03
Explain all options.	03
 Provide information.	 04
Explain things clearly/thoroughly.	04
Answer questions.	04
Know all the options.	04
Explain how treatment will affect them . . .	04
Give advice.	04
Provide correct information.	04
Be communicative.	04
Use layperson's terms.	04
Interpret test results for patients.	04
Talk to patients, make sure they understand.	04
Help pick specialists.	04

Ability/knowledge/skills/competence.	05
Continue to study/learn.	05
Give good care.	05
Get rid of cancer.	05
Check patients frequently.	05
Do a needle biopsy first.	05
Do your best.	05
Talk with other MD's.	05
Examine well.	05
Follow-up.	05
Encourage prevention (i.e. annual mammograms).	05
Examine patients thoroughly and often.	05
Be sure of your diagnosis.	05
Insist patient does exercisers (after surgery).	05
 Get a Second Opinion.	 06
 Work with primary care physician.	 07
 Act promptly.	 08
Take care of it right away.	08
 Can't Do Anything For Patients/Nothing.	 09
 (No Code 10)	
 Specific Screening/ Treatment Recommendations.	 11-95
Mastectomy.	11
Breast conserving surgery.	12
Chemotherapy.	13
Radiation Therapy.	14
Tamoxifen.	15
Test lymph nodes.	16
No radiation.	17
No reconstruction.	18
Better cosmetic outcome.	19
Don't know.	95

Patient ID ____/____/____/____
National Survey

Thank you for taking the time to answer these questions. Your participation has been invaluable and will help many other older women like yourself.

1) Would you like us to send you a summary of the results of the project?

Yes 01

No 00

Unsure 88

2) Would you be willing to be contacted again in the future for a similar project?

Yes 01 (OBTAIN CONTACT INFO)

No 00

Unsure 88

TIME ENDED: ____:____ AM/PM

Do you have any questions for me?

[REFER ALL QUESTIONS REGARDING CANCER AND IT'S TREATMENT TO 1-800-4CANCER]

Appendix 3

The National Physician Survey Instrument

Section I — CLINICAL SCENARIOS: THE FOLLOWING 3 SCENARIOS ASK FOR YOUR OPINIONS ABOUT TREATMENT OF HYPOTHETICAL ELDERLY PATIENTS.

A. Scenario 1: A 73 year-old woman presents with a lesion seen in the upper, inner quadrant of the left breast seen on screening mammography. The mammogram was done because her neighbor in the retirement community developed breast cancer. On physical examination, no masses are palpable in the breast, and she has no adenopathy. A needle-localization biopsy is done revealing a 1.0 cm well-differentiated infiltrating ductal carcinoma. Margins of excision are negative. The tumor is ER-positive, PR-positive, diploid and with an S-phase of 2.7%. She has a long-standing history of diabetes mellitus and has been treated for foot ulcers. She lives in her own apartment in the retirement community. The management provides transportation to medical appointments.

We recognize that many factors, particularly patient preference, go into a treatment decision. However, **please answer the following questions indicating which treatment you would prefer the patient undergo.**

PLEASE CIRCLE ONE FOR EACH QUESTION	
1. Local therapy	
1 Breast conserving surgery	
2 Breast conserving surgery and radiation	
3 Mastectomy (with or without reconstruction)	
2. Would you recommend surgery to evaluate the axillary nodes?	
1 Yes	
2 No —————> Skip to 5	
3 If axillary surgery is done and the nodes are negative, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	
4. If axillary surgery is done and the nodes are positive, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	
5. If axillary surgery is not done, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	

A. Scenario 2: A 74 year-old widowed woman with no underlying medical problems presents with a 1.5 cm palpable mass in the sub-areolar region of the right breast. There is no nipple discharge. On examination, this subareolar mass is palpable, but there are no other masses, and there is no palpable adenopathy. Her breasts are large. The mammogram confirms the presence of the sub-areolar mass but shows no other abnormalities. True-cut core biopsy of the tumor reveals a moderately differentiated adenocarcinoma. The tumor is ER-positive, PR-negative, aneuploid and with an S-Phase of 12%.

We recognize that many factors, particularly patient preference, go into a treatment decision. However, **please answer the following questions indicating which treatment you would prefer the patient undergo.**

PLEASE CIRCLE ONE FOR EACH QUESTION	
1. Local therapy	
1 Breast conserving surgery	
2 Breast conserving surgery and radiation	
3 Mastectomy (with or without reconstruction)	
2. Would you recommend surgery to evaluate the axillary nodes?	
1 Yes	
2 No —————> Skip to 5	
3. If axillary surgery is done and the nodes are negative, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	
4. If axillary surgery is done and the nodes are positive, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	
5. If axillary surgery is not done, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	

A. Scenario 3: A 70 year-old married woman with no past medical history presents with a palpable mass in the upper outer quadrant of the right breast. Clinically, the axillary nodes are negative. The mammogram reveals an isolated mass. The patient undergoes an excisional biopsy that reveals a 2.5 x 2.0 x 1.0 cm moderately differentiated infiltrating ductal carcinoma with extensive intraductal carcinoma within and around the invasive component. The specimen size measures 3.5 x 2.5 x 1.5 cm and the margins are microscopically negative. The invasive tumor is ER-negative, PR-negative. The invasive tumor is aneuploid and the S-phase is 11%.

We recognize that many factors, particularly patient preference, go into a treatment decision. However, please answer the following questions indicating which treatment you would prefer the patient undergo.

PLEASE CIRCLE ONE FOR EACH QUESTION	
1. Local therapy	
1 Breast conserving surgery	
2 Breast conserving surgery and radiation	
3 Mastectomy (with or without reconstruction)	
2. Would you recommend surgery to evaluate the axillary nodes?	
1 Yes	
2 No —————> Skip to 5	
3. If axillary surgery is done and the nodes are negative, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	
4. If axillary surgery is done and the nodes are positive, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	
5. If axillary surgery is not done, would you recommend:	
1 Tamoxifen	
2 Chemotherapy	
3 Both	
4 Neither	

Section II -PATIENT PARTICIPATION*

: The next set of questions are about patient involvement in treatment decisions. There are no right or wrong answers. Please indicate on a scale from 1 to 5, whether and how strongly you agree or disagree with each statement.

MARK (X) FOR EACH		Strongly Agree			Strongly Disagree	
1.	Patients may lose confidence in their physician if they believe that he/she has no firm opinion about the best treatment.	1	2	3	4	5
2.	Patients who participate in treatment decisions have a better psychosocial adjustment to treatment than those who do not.	1	2	3	4	5
3.	Encouraging patients to participate often does more harm than good.	1	2	3	4	5
4.	Patients should have a greater influence on treatment decisions than should their doctors.	1	2	3	4	5
5.	Most patients want to have a greater role than their doctor in treatment decisions.	1	2	3	4	5
6.	Patients cannot possibly make good decisions because they cannot understand the information.	1	2	3	4	5
7.	Asking patients to participate in treatment decisions produce unnecessary stress for them.	1	2	3	4	5
8.	Patients who participate in treatment decision are less anxious and depressed during recovery.	1	2	3	4	5
9.	When given comprehensive medical information, patients make good decisions about treatment.	1	2	3	4	5
10.	Most patients definitely want to be involved in treatment decisions.	1	2	3	4	5
11.	Even if they are given enough information, most patients are too upset to understand it completely.	1	2	3	4	5

*Adapted, A. Liberati, 1995 (Am J Public Health 1991; 81:38-42; Tumori 1987; 73: 601-609)

Section III - DEMOGRAPHIC INFORMATION

1. Year of birth _____
2. Gender
 - 1 Male
 - 2 Female
3. Did you have residency training in surgical oncology in addition to your general surgery residency?
 - 1 Yes
 - 2 No
4. Are you affiliated with a: (Please check all that apply)

a. Teaching hospital	<input type="checkbox"/> Yes	<input type="checkbox"/> No
b. NCI-designated cancer center	<input type="checkbox"/> Yes	<input type="checkbox"/> No
c. Community cancer center	<input type="checkbox"/> Yes	<input type="checkbox"/> No
5. What is the number of breast cancer patients of all ages you treated in 1994. _____
6. What proportion of your breast cancer patients treated in 1994 were:

Less than 50 years old?	_____%
50 to 64 years old?	_____%
65 to 74 years old?	_____%
Greater than 74 years old?	_____%

The next 3 questions involve only the patients in your practice 65 and over with T₁/T₂ breast cancer and nodal status N₀/N₁ (either clinical or pathological) seen during 1994.

- 6a. What percentage received:

Breast-conserving surgery (BCS)	_____%
Mastectomy	_____%
- 6b. Of those that received BCS, what percentage received:

RT	_____%
No RT	_____%
- 6c. What percentage of patients received:

Axillary dissection	_____%
No axillary dissection	_____%
7. Regardless of local treatment options, what percentage received:

Tamoxifen	_____%
No tamoxifen	_____%
8. Regardless of local treatment options, what percentage received:
(Including node-negative, positive, and nodal status unknown patients)

Chemotherapy	_____%
No chemotherapy	_____%

Thank you for your time.